Ethical dilemmas with premature babies

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Part one looks at some usual ways of discussing ethical dilemmas.
pt 2 looks at other important but often neglected ways of considering ethics
apologies to people here who know a great deal about ethics I hope this mini-guide will serve as a background for this morning to remind you of different ways of looking at the dilemmas that will be discussed during the conference.

Ethics problem is that the word ethics sounds high powered and people often switch-off and say `oh I don't know anything about that'.

problem made worse by the way so many philosophy departments now run academic ethics courses, which could suggest only academics can understand ethics.

This is dreadful because it is not true and because ethics is far too important to leave to academics.

Ethics is the stuff of life. Pre school children talk about ethics when they argue whose biscuit is the biggest `that's not fair' - justice, fair share of resources.

If they quarrel and they say `you're not my best friend any more'. They are talking about respect for autonomy, and about kindness or beneficence.

A toddler learning to share toys with a new brother or sister has to weigh up the harms and benefits. Sharing means that mummy will be pleased and the baby might stop crying, not sharing means that mummy might be cross but the toys won't be so chewed up by the baby.

Ethicists translate common sense everyday ideas into fancy terms, in ways that are not always helpful. But the main frameworks are quite simple and knowing them can help to resolve endless debating at cross purposes.

Basically main stream ethics courses rely on 3 forms of argument.

Rights

Rights questions include: Do premature babies have the right to very costly intensive treatment?

Do they all have the right to basic nursing care to keep them alive, however severely impaired they may be?

Do they have the right to die?

If they are not enough ventilators, which of three possible patients has the greater right to receive ventilation?

Do parents have the right to refuse to allow their baby to have life-saving treatment?

Do new born babies have the right to consume health care resources which might be better spent on other groups such as frail elderly people?

Some people are irritated by this approach, saying you cannot set up the rights of a baby against a mother or against other babies. In battling about competing rights there is a risk of just mindlessly shouting opposing slogans - as outside abortion clinics - which only ends in more bitter disagreement instead of finding some solution.

Yet the rights movement has transformed attitudes towards babies. In Roman times the new child was laid on the doorstep for the father to decide whether to accept it into the family or reject it. Today, the international agreed convention on the rights of the child asserts that the primary consideration for each child must be his or her best interests. In all matters affecting them, children who are capable of forming their own views shall be heard and respected, and this includes teenage parents of premature babies. Every child has an inherent right to life, and to maximum state efforts to ensue survival and development of the child, and the enjoyment of the highest attainable standards of health., and to health care services. This includes promoting breast feeding, preventing accidents and disease, and so on.

No one has the right to refuse life-saving tretment for a baby. This is a matter of responsibility and trying to decide in the child's best intersts. On a general level, rights language has benefitted countless children, at an individual level it can be rather crude.

Duties

The oldest way of looking at ethical questions, since before Plato's time is through duties, the language of ought and should.

- What kinds of care should parents and health professionals give to premature babies?
- What kinds of treatment ought to be given or withheld?
- When ought seemingly hopeless, painful treatment be withdrawn?

People who emphasise duties call themselves deontologists. They tend to prefer clear, general rules; everyone in a certain group should be treated in a certain way to be fair. They group all duties under 3 main headings:

justice
respect for autonomy
do no harm

The headings cover duties such as sharing out resources fairly, truth telling, avoiding neglect or abuse, and so on. They are ideal standards to live by. Yet they raise problems. People argue over conflicting duties. When you inform parents of a premature baby about the serious risks of treatment are you respecting them, or harming them?

Some say that it is our duty to preserve all life, particularly in North America. Others say that prolonging unhelpful treatment is extremely cruel, `we are torturing our babies to life' said one mother in a USA neonatal unit. They argue that quality of life comes before sanctity of life at any price, and respect means helping babies to have lives worth living, not keeping than alive at any cost.

Respect is a problem with babies. How can you respect a baby's autonomy? Debates about autonomy slip into endless arguments about what is autonomy, do only fully developed persons have it, are babies persons? and so on. Some well-know philosophers say that babies cannot speak, or therefore think, and therefore are not persons and it is not wrong to end their life.

Over the centuries rising ideals about duties have helped to protect women and babies from gross abuse and neglect, and to encourage high standards of care, say in hospitals and community health care. Yet duties are not always helpful when trying to decide what is the best kind of care for a particular baby. Indeed duties-based arguments have been criticised for being very impersonal, and intellectual, stressing non-interference -whereas premature babies are very dependent and need a lot of intrusive care. Talk of duties to respect and not to interfere, which suited philosophers 200 or more years ago, does not suit babies and anxious new parents. Many doctors and nurses see their work as going beyond basic impersonal duty, into concern for particular families sensitively helping them to cope with their distress.

Harm/benefit

Rights and duties can work like rigid rules which must be followed, when adults caring for babies are expected to look back over their shoulders at the expert rulings drawn up in the past by philosophers, lawyers, health managers and other authorities.

A third framework is more popular and that involves looking forward to outcome. What kinds of care are most likely to result in a healthy, happy childhood and adulthood?

Outcome is calculated by weighing the harms of giving or withholding treatment, against the hoped-for benefits. When harms and benefits are counted in this way, they are seen as values or utilities, so the third framework is called utilitarianism, and everyone uses this method daily. A father in a corridor is looking very upset, a passing nurse thinks, `shall I stop to try to help him, that family needs a lot of support, or shall I hurry past because I'm late for the planning meeting about the new parents' rest room?' Part of the balance is how useful the nurse can be either to the father or at the meeting, another balance is do you try to benefit one person or, potentially through planning the room, many parents.

There are many problems with this method of thinking. If an approach benefits most people, like early discharge which is preferred by most patients and tax payers and health managers, the minority tend to be ignored. This method is not interested in absolute values, such as always tell the truth. Truth is less important than the effect of telling it will have, it might frighten people, or lead them to demand much more discussion time before they decide about treatment. Although absolute values can be harsh, such as insisting that everyone knows about major risks, they can also support high standards which otherwise slip. Otherwise, in utilitarianism you can allow that `anything goes' as long as someone believes it will bring the best results, or be the cheapest method.

Another problem is who decides what is best? And whose best outcome do you aim for? For the baby to survive but be very impaired? For the parents to be freed of a burden of a handicapped child, or to insist on keeping alive their child who may face a miserable life? For a specialist unit to develop skills in new high risk treatments, for society to reduce high costs of care. Guys breakthrough on Downs markers publicised with life-ling cost of caring for someone with Downs. As well who benefits, it is not clear what benefits are counted and who defines them as harms and benefits.

Most harms and benefits cannot be exactly defined or measured or balanced against one another in the way utilitarians assume. For example when considering a heart transplant for a baby who will otherwise die. How can you measure the harm of death against the harms of painful, prolonged and very probably ineffective treatment? Not only are these enormous concepts, people vary in which they believe to be the worst fate. Most people also cheat by blowing up the benefits and dismissing the harms to suit the answer they want. Most of all, outcome, the future, is uncertain, yet much ethics discussion carries on as if everything is clear and precise as long as you think clearly enough.

There are problems in all 3 mainstream methods.

The principles often conflict, and can be twisted to suit opposite arguments, for or against giving treatment or information.

They tend to be vague when it comes down to thinking about a particular baby.

They lead into long complicated discussions which may not arrive at any clear answers or agreement.

When this happens the cleverest or the loudest side usually wins but this does not mean that they are necessarily the wisest.

The 3 methods tend to ignore important moral questions about power, politics and history, about personal relations and communication, process and change, and about feeling and suffering, But I will stop now, and leave you to think about these 3 main approaches in relation to the next talks this morning.

Rights -	**to non-interference**
	to resources and care
	to protection from harm or neglect
Duties -	**justice**
(deontology)	**respect for autonomy**
	do no harm
Harm/benefit -	**choose for the best outcome**
(utilitarianism)	**for the baby, or parents,**
	for professionals, or society

2. Facing the ethical dilemmas

Earlier I talked about methods in ethics which look backwards to rules and laws, rights and duties, which have already been drawn up by experts. The other method is to look forward and try to base decisions on the best hoped-for outcome. In practice, most people use a mixture of all 3 methods. Tell the truth, Do not kill are duties which are usually observed unless there is a very strong reason for thinking that great harm will result. In this second part I will talk about two other directions for looking at ethics, outward and inward.

Outward

Politics and economics

Ethical questions about prematurity extend outside the health services. The needs and `rights' of premature babies are woven into many aspects of society. Prematurity is linked with poverty which in turn is linked with poor diet, bad housing and deprived communities. Research shows that many people do not need health education and good advice as much as they need an adequate income and living conditions. This would help towards preventing prematurity, and also help families to cope better after their baby has arrived early.

Prematurity is linked with higher rates of neonatal disease and disability. The prospect of caring for a handicapped child is, in some ways, becoming increasingly bleak. Former communities and family networks are more fragmented, so that a greater burden falls on parents and usually on mothers. Now that the health, social and education services are being broken up into small units, multi-handicapped children face extra problems. The costs of help with care are rising. There is a tendency to blame to victim. For instance a state survey of disabled people asks: Are you too disabled to use local buses? Rewritten by a man with disabilities the question becomes: Are the local buses too badly designed for you to use them? In the first view it is much worse to be disabled. It is fatalistic and discriminatory. Affected by such views, new parents and maternity staff may feel very gloomy about early defects, in ways which might affect the child's whole future.

Almost everything is being audited, with obvious benefits but also harms. Increasingly people are being seen as cost units. Just one example is the growing reluctance of GPs and dentists to take on new patients who may need extra care. Another example is the increase in antenatal screening; a powerful unspoken message to parents-to-be is: if you are not satisfied with the produce (the fetus) you can always try exchanging it for a later, better model. Quality and cost-consciousness inevitably shift generally accepted moral standards about whether a life is `worth-living' for the child or the family. We do not just take moral values out of the air, they change with each decade, as public attitudes towards abortion or organ transplants show.

Health resources

How should health resources best be rationed out among competing groups? This is a favourite topic among ethicists. Yet is it the right question, or at least the right emphasis? It accepts, instead of questioning, current views that we all want lower taxes, although this means massively higher costs for individuals in need, for coping with the after effects of widespread deprivation. It accepts current priorities in how public funds are spent. Yet people who insist that present economics cannot be questioned prop up systems which most directly harm young children. In the UK the number of children living in poverty is steadily rising. The same is happening throughout the world. Every time the world bank insists that poor countries cut spending on health, education and housing, babies are the first to die. It might seem political to raise these issues. It is equally political to choose to avoid them.

The ethics of politics can be summed up into two views. People tend to believe either that

> if only people were better, society would be better
> or if only society were better, people would be better.

The first view is about the power of the individual, the person, the family, the opted out and competing school or hospital. Health tends to be seen more and more as a personal responsibility, look after yourself, and not look after your neighbour.[i] If individuals are healthy, a healthy society will follow. This view was taken to its logical extreme in Germany in the mid-century,[ii] and now in former Yugoslavia, with ethnic cleansing. Get rid of the sick and unwanted elements in society and all will be well. This view is especially bad news for premature babies and all vulnerable dependent people who need a generous caring society if they are to survive and flourish.

The second view assumes that if a society has good houses and play areas, good schools and hospitals, a healthy environment, worthwhile employment opportunities, then physical and moral health increases, and people become better. This view is good news for babies and children who need extra health care and social support. To some extent both views are needed, but when individuals are prized too much at the expense of the common good, the weakest members are those with most to lose. Ethical questions about prematurity are based on assumptions about individuals versus society which have to be examined.

Power

A notable gap in main stream ethics is a proper reference to power. Philosophers talk as if informed patients can chat to health professionals on equal terms. Parents of premature babies can rarely do so. Besides being new to the whole complex experience, they frequently feel shocked, very anxious, distressed, dependent, perhaps embarrassed and guilty. Many belong to classes and ethnic groups who unfortunately feel inferior to doctors and nurses at the best of times.

There are also power relations between doctors and nurses. Such as when nurses are acutely aware of distress among families and want to change routines of care to help them. Yet this may be resisted by nurse managers or by senior doctors. Imbalance of power needs examining: the crucial question is whether professionals share their knowledge with families and try to make decisions with them, or use their knowledge to achieve what they decide is best. Some doctors are criticised for not giving enough information to parents. Another serious problem that follows from lack of communication is that doctors and nurses have less change to listen to families, to learn from them and to develop with them ways of providing more effective, appropriate care.

When professionals intervene in children's lives, they can do great good, but also great harm. Public trust in doctors, nurses, midwives and health visitors allows them quite wide freedoms. Now that people tend to have only one or two children, most parents are new to the whole experience of caring for a baby, and so are even more dependent on professionals and have difficulty in questioning professionals' decisions. For all these reasons there is greater onus on health professionals to try to ensure that they `first do no harm' whenever possible. Recently I have been seeing a health visitor, step by step, discourage a new mother from breast feeding and advise starting bottle feeds, `just a top up in the evening' at first. Good intentions do not necessarily prevent harms, as US neonatologists found when above average rates of child abuse were found in survivors of their neonatal unit. They traced the origins of some abuse back to the separation of mothers and babies after birth, and policies in neonatal units which separate mothers and babies are still slowly being changed.

The idea of abusive parents is now widely accepted, but it seems to much harder for professionals to accept that they too can abuse babies and abuse their position of power. One way to reduce this is by stringent follow up and evaluation. The largest review of this kind assessed numerous perinatal practices for whether they: reduce poor outcomes; seem promising but are of unproven benefit; are used but the outcome is not known; should be abandoned in the light of available evidence.[iii] Researchers are disappointed that their findings are so often ignored, and old-fashioned practices persist in spite of being shown to be useless or even harmful. Ethical care for all babies surely includes careful, regular review, mainly of two kinds: of the journals to check that useful research findings are put into practice; and of polices and practice in each neonatal unit and of each professional through following up individual babies. This personal evaluation includes listening to parents and being willing to revise practices in the light of their experiences.

In the US ethicists act as consultants to advise neonatologists wondering whether to continue or withhold treatment from certain babies. One neonatologist told me: `In the morning I conduct my clinical round, and in the afternoon I take my ethical round'. Are clinical and ethical matters so distinct? What is the effect on the family, an undue proportion of them have little formal education and may speak little American, of high-powered, highly educated ethicists influencing medical decisions about their baby. This could easily be an abuse of power, exclusive use of knowledge by professionals to justify whatever they decide to do, possibly using knowledge to intimidate families instead of to learn and to share in making decisions.

Empowerment is a current buzz word, but it is meaningless. Often it simply means being polite to someone, shaking hands with a women in labour and introducing yourself is about politeness but not about power. You can take away life or destroy a reputation, but you cannot give someone life, or make their reputation for them, only they can do that. The same with power. It is energy inside that person which cannot be given or conjured up by others, but can be stifled. You can undermine people's power by keeping them in ignorance and excluding them from decision-making. Yet giving information is just that, giving information, and should not be confused with giving power. What is this thing called power which people who talk about `empowering' have to give away? It would be more useful to think about how professionals can stop taking away patients' power and can be prepared to do with less power themselves. For example, how would midwives feel if the women they seek to `empower' all decided to boycott over-crowded antenatal clinics?

Ethics is too much concerned with the content of discussions about neonatal treatment. A first concern is the context of the discussions. What access and accommodation do parents have to ensure that they can be present at the discussions, and through feeling welcomed, respected members of the caring teat can listen and contribute on fairly equal terms? Are medical concepts explained in lay terms? What is the pace and tone of the discussion? Recently I heard some gynaecologists debating the ethics of women's rights to amniocentesis. They were all shouting each other down. Is that how they hold discussions with their patients?

In talking about looking outwards, I've very briefly mentioned a few aspects of the political and economic context, current ethical beliefs about health in its broadest sense, quality of life, professional power and knowledge and professionals relationships with families, as well as hospital policies and practice, evaluation and efforts to raise standards. All these issues raise questions about ethics. Many also relate to the final part of this paper: looking inwards.

Inwards

Caring for premature babies can be stressful and distressing, caring for their anxious parents, coping with limited resources and perhaps most difficult of all uncertainty when no one is sure how certain babies will respond to treatment. Support groups for nurses can be a valuable way of helping them to cope with the stress partly through becoming more aware of their own feelings and sharing these with their colleagues.

Over the decades nursing has been transformed from rather impersonal detachment to a willingness to become involved with families. As a result, families are able to benefit from more sensitive, appropriate care and to receive far more support. Parents who are encouraged to become involved from the start with their baby, find that even if the baby dies they look back with less regret than parents who used to be told, `go home and forget about it'.[iv] When parents are around care becomes more humane. For example, it was through campaigns by American mothers that doctors stopped doing surgery on premature babies who were not adequately anaesthetized. Pain relief after surgery is also improving. A recent report by surgeons and anaesthetists stated that `Failure to relieve pain is ethically and morally unacceptable'. Yet coming to appreciate intense pain happens through a process of identifying and empathising with patients, quite different from the remote `clinical detachment' which used to be advocated. Today's approach seems to be far more ethical, in the sense of respecting everyone concerned, including the baby. Yet it raises moral questions about how much to become involved. `Do I break down and cry with the parents, or try to be a strong support for them?' is a question for nurses.[v] The way that nurses are now encouraged to ask such questions and to work together in finding answers seems to me an important ethical exercise.

Main stream ethics tends to ignore feelings and to over-emphasise the intellect. As women philosophers have pointed out, feelings play an important part in ethics. Concern at a baby's distress, anger about injustice, agonizing over which is the best option all heighten awareness and the urgent need to think about the best response to make. Parents' grief about their sick baby impels them to try to share with professionals in making the right decision. If they were not upset, they wouldn't be understanding the real meaning.[vi] Because feelings can be so useful, it is important when thinking about ethics also to look inwards, and to reflect on why you are feeling upset, scared, irritated, excited or whatever. This can be a source of insight and a way of avoiding ignorance or hypocrisy about your true position. Taking risks is threatening, and it is helpful to make time to come to terms with the fear.

It is very hard to change hospitals, routines quickly seem to become set in concrete. One example is the years taken to persuade hospital staff to agree that a parents can go with the baby into the anaesthetic room. Researchers claim that a major reason for resisting change is anxiety, even subconscious panic that everything will fall apart if routines are altered.[vii] This is also a reason why it is so hard for professionals find it so hard to let go of power; which can seem like betraying their responsibility.

So if ethics are to be taken seriously, and put to practical effect, such as by raising standards of care and standards of informed professional awareness, it is important to look inward, at you own feelings, fears and hopes, to look outward at hospital and health service policies, and further at attitudes in society towards health, illness and disability, besides looking (in a way) backwards towards laws, guidelines and rights agreed by past experts, and forwards to the hope of the best possible outcome for each baby and family. A task that is impossible to achieve fully, but one that I expect you find is worth attempting, because you are probably already doing all these things.

Ethical dilemmas are about uncertainties, hopes and fears, conflicting values. The horns of a dilemma by definition means that there is no single correct answers. Each answer has problems and advantages, and you cannot choose one without losing the advantages of another answer. The aim is to try to choose the least harmful way.

Traditional ethics is useful but is rather like trying to teach people to be better drivers by explaining what is going on under the car bonnet, the technicalities and mechanics of thinking. If you want people to better drivers, a more direct way is to show them and encourage much experience with driving skills. Everyone here is an expert in ethics, and so are the parents and many patients you meet. It is part of being human. A good way to increase skills is to practice listening to people with respect, appreciating their viewpoint and values, looking for common ground and ways of meeting in agreement about what <u>seems</u> the best decision to make for premature babies with their families.

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