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## EDUCATION ISSUES

# The care of the pre-viable and questionably viable infant – A midwife and a neonatal nurse dilemma

Doreen Crawford\*, Moira McLean

*School of Nursing and Midwifery, Faculty of Health and Life Sciences,  
De Montfort University Leicester, UK*

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### KEYWORDS

Viability;  
Pre-viability;  
Ethical dilemma;  
Resuscitation;  
Withdrawing support;  
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**Abstract** This article is intended to stimulate debate and suggest areas of perinatal and neonatal practice which could be usefully reviewed. There are legal and ethical constraints on current practice and arguably this is not always in the best interest of the neonate. Given that current technology has limits we need to be realistic as to the success of our current forms of management. While not wishing to stifle research and progress in any way, we as midwives and neonatal nurses, need to be kind and not inflict suffering on the infants most directly involved and their families.

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This paper is intended to stimulate debate and suggest areas of perinatal practice which could be usefully reviewed. It is not an exhaustive review on the topic of viability and will not cover the various ethical perspectives of value and sanctity of life but will consider some of the dilemmas faced by professionals working with this unique group of patients. A dilemma can be defined as an uncomfortable choice, as opposed to a problem, which can be more clearly, sometimes easily, solved. In nursing and

midwifery, a dilemma frequently incorporates a human element. A dilemma is seldom free from the practitioners own values, principles and feelings which inform an individual's daily life and can carry over and influence the professional role.

Without doubt the past few decades have been exciting and challenging ones for nurses and midwives working in Neonatal Intensive Care Units (NICU). With advances in technology and pharmacology, sicker, smaller and more premature infants have survived. This has not escaped the notice of the general public and media stories of "miracle babies" have become commonplace, arguably this

\* Corresponding author.

E-mail address: [dcraw@dmu.ac.uk](mailto:dcraw@dmu.ac.uk) (D. Crawford).

has lead to profound lay misconceptions of what is possible.

### Infants as hostages to technology?

It is contentious to say, but increasingly recognised within the neonatal speciality, that the boundaries of what is possible with the current technologies have been reached. Current technology cannot compensate, replace or augment the natural embryological developmental sequencing. Quite simply if the systems of circulation and oxygenation are insufficiently developed and mature to support life there is a big difference between viability, vitality and sustainability. In a seemingly cruel biological twist the pre-viable infants neuro-endocrinological systems are sufficiently developed for unpleasant stimulus to be transmitted, received and processed so these infants do feel pain and can experience distress. It is this potential for causing pain and distress to no future benefit which has led many professionals working in this speciality to question current practice.

### Quality of life issues

The publication of the [Nuffield Council on Bioethics \(2006\)](#) was a milestone in the ethical issues surrounding the case of the pre-viable and questionably viable infant of extremely low gestational age (ELGA). This report emerged at a time when increasingly experienced nurses and midwives were feeling that if what was being done to sustain and prolong life was ultimately futile we should at least have the courage to acknowledge this and work in partnership with the families and

our medical colleagues in order to be kind and act in the best interests of the infant. The report made several very pertinent and valuable points and it is up to the professions to utilise this resource and translate it into working frameworks and guidelines which can be applied in the clinical areas.

Although new data is continually being generated and academic discussion with regards to the extent of skew and bias within these studies continue ([Draper, 2009](#); [Evans and Levine, 2001](#)), there are also real limitations with the UK data being generated. [Draper \(2009\)](#) commented that part way through 2007 the data collection for the Confidential Enquiry into Maternal and Child Health (CEMACH) limited its data collection to stillbirths and neonatal death, i.e. excluding 22 and 23 week late foetal losses, due to reduced funding. However studies continue to indicate poor survival rates and high morbidity in the ELGA. For example using the data below of the 138 infants of 22–23 weeks gestation who demonstrated signs of life at birth, only two survived to be discharged from hospital, one with severe disability and the other with what was regarded as minor impairment. The figures were little better for the 23–24 week gestation infants with 90% of them deceased before their sixth birthday and only 1% of the survivors assessed as having no impairment. These figures are crude, but hard data and such facts are difficult to argue against, yet behind these stark figures are real families and their much loved infants and a great deal of commitment and dedication from various professional groups and a disproportionate slice of increasingly scarce NHS funds. When it comes to neonatal care and outcomes, it could be said, as the volume of information increases so do the dilemmas ([Watts and Saigal, 2006](#)).

Outcome	Weeks gestation			
	22–23	23–24	24–25	25–26
Showed signs of life at birth	138 (100%)	241 (100%)	382 (100%)	424 (100%)
Survived to discharge from hospital	2 (1%)	26 (11%)	100 (26%)	186 (44%)
Died by age of 6 years	136 (99%)	216 (90%)	284 (74%)	241 (57%)
Survived at 6 years with severe disability	1 (0.7%)	5 (2%)	21 (5%)	26 (6%)
Survived at 6 years with moderate disability	0	9 (4%)	16 (4%)	32 (8%)
Survived at 6 years with mild disability	1 (0.7%)	5 (2%)	26 (7%)	51 (12%)
Survived at 6 years with no impairment	0	3 (1%)	10 (3%)	35 (8%)

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