

UNIVERSITY OF
TECHNOLOGY SYDNEY

TOO YOUNG TO LIVE?

UTS
THINK.CHANGE.DO

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“the special vulnerability of very premature infants under the assault of modern intensive care techniques evokes strong responses: both the desire to sustain their fragile existence and doubts about the wisdom of doing so...” (McCormick, 1994).

In November 2006 NSW neonatologists released a consensus statement

there is a “grey zone between 23 weeks’ and 25 weeks and 6 days’ gestation. While there is an increasing obligation to treat with increasing length of gestation, it is acceptable medical practice not to initiate intensive care during this period if parents so wish, after appropriate counselling.”

Lui, K., Bajuk, B., Foster, K., Gaston, A., Kent, A., Sinn, J., Spence, K., Fischer, W. & Henderson-Smart, D. 2006a, 'Perinatal care at the borderline of viability: A consensus statement based on a NSW and ACT consensus workshop', *Medical Journal of Australia*, vol. 185, no. 9, Nov, pp. 495-500.

Television shows such as “Saving Babies” give parents false hope and fosters unrealistic expectations in the general public who assume that all babies can be saved.

BACKGROUND

DEFINITIONS

- Low birth weight (LBW) <2500 grams
- Very low birth weight (VLBW) <1500 grams
- Extremely low birth weight infants (ELBW) <1000 grams

DEFINITIONS

- Term = 37-42 weeks gestation (normal length of pregnancy)
- Preterm is less than 37 weeks gestation
- The average newborn at term weighs 3.2kg
- Babies greater than 34 weeks gestation are unlikely to have problems

- **The more premature the baby the more likely there will be major problems.**

VIABILITY

- The World Health Organisation (WHO) in 1977 defined viability as a fetus having reached a birth weight of 500 grams or more
- At a birth weight of 500 grams the gestation is generally thought to be 22 weeks.

AUSTRALIAN LAW – WHY IS 20 WEEKS IMPORTANT?

- Babies of 20 weeks gestation **CANNOT** survive
- 20 weeks is a critical time for neurological system development
- 20 weeks bestows moral value on the developing baby
- The “potential” of the developing human



<http://www.sciencemuseum.org.uk/on-line/lifecycle/images/1-2-3-1-9-0-0-0-0-0-0.jpg>

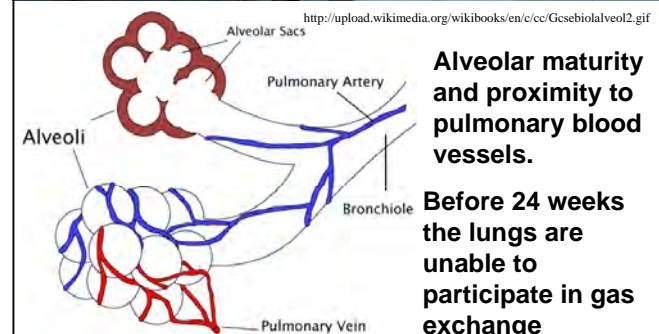
AUSTRALIAN LAW - VIABILITY

- The potential of the **FETUS** to survive outside the **UTERUS** after birth.
- 20 weeks gestation
- The time after which termination of pregnancy is illegal except for lethal abnormalities (anencephaly)



<http://www.sciencemuseum.org.uk/on-line/lifecycle/images/1-2-3-1-9-0-0-0-0-0-0.jpg>

WHAT DETERMINES WHETHER A BABY WILL SURVIVE?

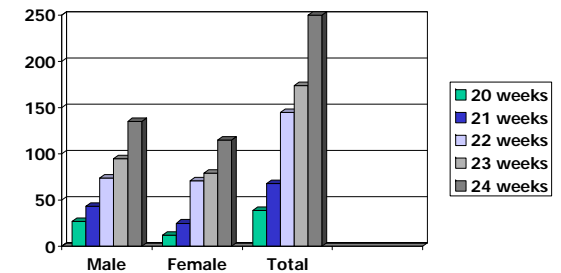


There are some babies who are too young to live

WHY ARE BABIES BORN EXTREMELY PREMATURE?

- In many cases there are no identified risk factors
- Mothers who seek early and regular antenatal care are less likely to have a premature baby
- Maternal socio-economic status and education level
- Assisted reproductive technology
- Multiple gestation

THE NUMBER OF INFANTS OF MARGINAL VIABILITY IN AUSTRALIA



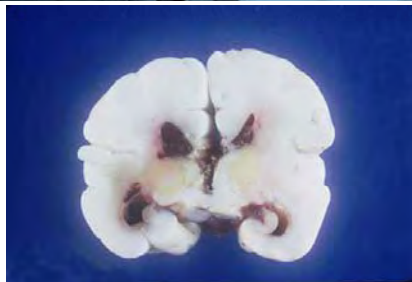
SURVIVAL

- Infants born at 23 weeks gestation have a 30% chance of survival → of 100 infants born 30 will survive.
- Infants born at 24 weeks gestation have a 50% chance of living → of 100 infants born 50 will survive.
- Survival is not an indication of outcome – survival for the purpose of statistics means **ALIVE**

MAJOR PROBLEMS OF BABIES OF EXTREME PREMATURITY

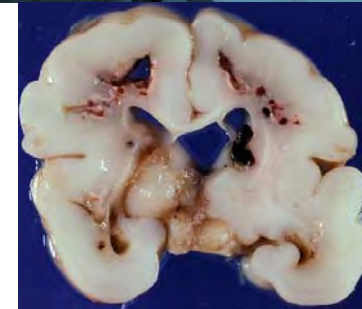
- Lack of lung and other organ development
- Intraventricular haemorrhage
 - brain injury
 - severe cerebral palsy
- Necrotising enterocolitis
- Severe disability

INTRAVENTRICULAR HAEMORRHAGE



www.path.sunysb.edu/.../woz/NPERESS/slide098.jpg

PERIVENTRICULAR LEUKOMALACIA



www.neuropathologyweb.org/.../54g-PVL.jpg

NECROTISING ENTEROCOLITIS



upload.wikimedia.org/wikipedia/commons/4/43/N...

MY RESEARCH



24 week
gestation
fetus

Please remember that I am talking about babies of 24 weeks gestation and less only. This research is not generalisable to any other premature babies!

health.howstuffworks.com

WHY THE RESEARCH?

Neonatal nurses are beginning to question the value of aggressive neonatal intensive care for babies of marginal viability in light of recent outcome studies that show that these babies have a very real prospect for severe disability.

THE RESEARCH

- Questionnaire to all members of Australian Neonatal Nurses Association (ANNA)
- Q/A addressed issues related to:
 - feelings / attitudes / beliefs
 - ethical issues
 - social issues
 - legal issues
 - technology of the future

THE RESEARCH

- Major issues discovered from analysis of questionnaires (414 = 54% response rate)
- 14 Interviews – single / focus group
 - Perinatal centres (11)
 - NETS team (1)
 - Surgical centres (3)
- All from NSW - Sydney/Newcastle/Canberra
- Every large centre in NSW

NOTE: Not all extremely premature babies created ethical dilemmas for the neonatal nurses. Babies with the potential for a good outcome were rarely a source of ethical distress.

THE LAW

AUSTRALIAN LAW - VIABILITY

- There is no legal provision for treatment to be given when the effects of treatment can be said to outweigh benefits to the infant.

“I think the law is a tricky thing. I don’t think the law should make you resuscitate a baby who you know hasn’t got a great chance. They [lawyers] only see things in black and white. Viability, they’ve changed it to 20 weeks and so they’re viable 20 weeks, which I have a great problem with. I think they’ve made a bit of a rod for themselves there, saying ‘20 weeks you’re viable’”. (Nurse 16)

“The smaller they are...I think it’s more dangerous territory you’re getting into. I look at the pain that we inflict on them, even for the short time that we keep them alive before we decide that there’s no hope. We do create a lot of distress. There’s no doubt about it. (Nurse 13)

MEDICALLY INDICATED WITHDRAWAL OF TREATMENT

- **Attribution of the cause of death.**
- **If the baby’s death is legally attributed to the underlying condition (extreme prematurity), then no legal liability will follow.**

EXTRAORDINARY MEASURES

Defined as:

Medical or surgical measures that prolong life, or are intended to prolong life, by supplanting or maintaining the operation of bodily functions that are temporarily or permanently incapable of independent operation.

TERMINAL ILLNESS

Those patients whose medical condition is incurable and irreversible, and where the application of extraordinary measures would only serve to prolong the process of dying

“I don’t think you can legislate against life. It would be a very Big Brotherish to actually legislate against the sanctity of life in that way”. (Nurse 10)

“I don’t think the law should make a blanket statement. Every case is different.” (Nurse 11).

“What would they [law] say? ‘Oh, if they’re breathing below 24 weeks, you’ve got to do something.’ I mean lots of babies [24 weeks and less] breathe, but they’re rarely functional”. (Nurse 18)

THE MYTH OF THE MIRACLE BABY

MIRACLE:

- an effect or extraordinary event in the physical world that surpasses all known human or natural powers and is ascribed to a supernatural cause.
- such an effect or event manifesting or considered as a work of God.
- a wonder; marvel.

<http://dictionary.reference.com/browse/miracle>



Kimberley Mueller – weighed 10 ounces (283.5g)
Born in Hanover Germany

1.bp.blogspot.com/.../bab1BILD2709_468x302.jpg

Guinness Book of World Records



Rumaisa Rahman (USA) born Sep 2004 (15 weeks premature) is the world's smallest surviving baby at 8.6oz (243.8g)



Amilia Sonja Taylor
The world's most premature baby

Length: 23 cm long
BW: 284.0 grams
Gestation: 21 weeks and 6 days
Born: 6th October 2006

www.theage.com.au

“...the ordinary Mr and Mrs Joe don’t know anything about a 23 weeker except what’s in the magazines.” (Nurse 19).

“...quite dangerous because people then expect every 24 weeker to survive and... be perfect and healthy, which we can’t guarantee.”(Nurse 12).

“Usually they get the good stories. They rarely get the bad ones, because the bad ones people don’t want to talk about it. Media stories are generally good ones, because they want feel-good stories. But rarely is a negative one shown... I think it’s all of the really nice feel good stories is what they get.” (Nurse 24)



www.theage.com.au



www.smh.com.au

**THE MYTH OF THE MIRACLE BABY –
EXAMPLES FROM THE INTERNET**



'Miracle Baby' graces
New Year's cover

There is even a miracle baby toy.....

Mini Miracle Baby Nursery Playset



*“Of course, the parents are going to say, ‘Oh well, yes we wouldn’t change it for the world.’ I mean, are they going to say in those sort of women’s magazines, ‘Oh, no, we wish we’d never saved our child.’”
(Nurse 16)*



HOPE – AND PRAYING FOR A MIRACLE

“It [baby] probably wouldn’t even be able to do anything, and would probably be a baby for the rest of his life if he survived. And there was this mother saying, ‘God will send me a miracle’.”
(Nurse 16)

“We’ve never actually withdrawn treatment until the parents are ready and they’ve decided that there’s nothing else that can be possibly done. We’ve done everything. We’ve waited those extra few days, prayed for a miracle. It’s not going to happen.” (Nurse 20)

RESEARCH “V” EXPERIMENTATION



www.vivo.colostate.edu/.../placenta/leonardo.jpg

“I think doctors will say ‘Well we’ll see how far we can go with this one, what we can actually do.’ I don’t think that’s very nice for the baby involved. I think we should have a little bit more respect for the life.” (Nurse 17)



1.bp.blogspot.com/.../bab1BILD2709_468x302.jpg

“Just keeping them alive is a form of experimentation.”
(Nurse 17).

“I know that we did have a baby come over from [name of hospital]. It was 24 weeks and did peritoneal dialysis on it. And it was purely experimental and the doctor accepted the baby on that proviso, but never asked the nurses would they be happy to do it and they were horrified that they had to do it and the baby ended up dying of course.” (Nurse 17)

Necrotising fasciitis - "Coming up from the feet and it's such a fast progress of a condition and it was up to its lower part of its abdomen. They were getting everyone to come and see it. They wanted to write this paper on the baby, because it was such a rare thing on a 24 week neonate." (Nurse 11)

"Worst major pulmonary haemorrhage I've ever seen in my life. It was the type that bleeds right down into the ventilator tubing. You can't ventilate and we were told to keep going, keep going, because this baby has to survive. And it was only because they wanted this paper to be written." (Nurse 11)

"I can remember I got into trouble, because I disconnected the PEEP (positive end expiratory ventilator pressure) and this baby would die because of that and now what's going to happen with research, with this paper that they wanted to write. And feeling like that I was being accused of killing this patient." (Nurse 11)

"It still was as fresh in my mind as like yesterday ...to me that was experimenting and it was wrong". (Nurse 11)

“Just to keep them alive to say ‘Look how clever we are’. I find that horrid and I hate it, yeah I hate it.’ (Nurse 9)

“You just wonder how much the parents would tolerate if they knew some of those things and experimenting. I know they’ve got to learn, but it’s how they learn.” (Nurse 9)

“When experimenting goes on in such a way that the baby is going to suffer, or they’re just extending the suffering, that’s when it really gets a bit hard to swallow.” (Nurse 9)

“It was his attitude. He didn’t want to know about our concerns for the baby. All he was interested in was doing that study.” (Nurse 13)

WHEN CARING AND TORTURE ARE THE SAME THING

Nurses feel they are torturing prem babies



Working against the odds all worthwhile for Melissa

Pengally, J. 2001, *The Advertiser* (Adelaide), Wed 7th Nov, p. 9

TORTURE

- To cause extreme physical pain
- To give mental anguish to
- To twist into a grotesque form

VERB: afflict, agonise, distress, excruciate, pain, persecute, torment.

NOUN: affliction, agony, anguish, distress, hell, misery, pain, suffering, torment.

Collins Concise Dictionary, 2001, 5th Australian Edn, p.1593.

The morning after the night when I was prematurely ejected from my mothers womb during a violent tempest...I awoke to find myself in many pieces, pinioned to the incubator floor, with my several senses separately trapped in distinct forms of torture: my eyes shut against the insufferable brightness, my mouth scorched by dryness, my skin scratched by roughness, the sensitive mucosae of my nose crudely pierced by foreign tubes....Only pain made any link between my senses so that I could recognise they were all functions of myself, me.

Harris Williams, M. 1994, 'The ugly duckling', in The Newborn in the Intensive Care Unit: A Neuropsychanalytic Prevention Model, ed. R. Negri, The Clunie Press. p. xvii.

“Because it looks so perfect... and it is, to the outside world or on the outside. But it’s what we do to screw it up inside that makes the difference. And we do. It’s iatrogenic. A lot of their problems. I mean we do it ... all in an effort to make them well, I realise that. And I’ll continue doing it. But we do some terrible things to them.” (Nurse 21)

“But that’s what it’s like, isn’t it? It’s like torture you think the baby is going through.... if the baby is that sick, I know it’s really cruel and really tortuous,” (Nurse 19)

“The grimacing and the .. the drawing away and ... I mean still we ... do terrible things to them.” (Nurse 21)

“It concerns us a lot too. Those babies are still going to need .. reintubating with a tube ... they’re still going to need some long lines replacing, you know blood taken and whatever. No one wants to torture a baby just for no good reason because it’s going to be a futile outcome.” (Nurse 20)

“Yeah I guess I compensate a lot by thinking ‘Well .. they’re probably brain dead anyway.’ Because we’re .. you know the gases (arterial blood gases) are so dreadful and well I guess I just keep telling myself you hope that they’re brain dead. Well that’s the only way that you can cope with it.” (Nurse 23)

“I remember one baby that someone was looking after and she just refused to look after it. And she said so to the neonatologist. She said she couldn’t agree with what was going on and she refused to look after that baby anymore.” (Nurse 14)

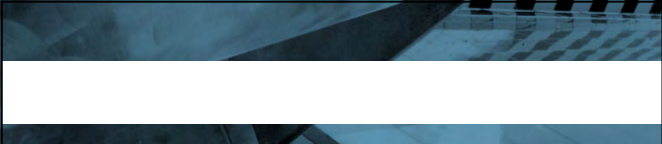
CONCLUSION

- **Many babies of extreme prematurity do not have the requisite maturity to survive.**
- **Parents need counselling to help them understand what will/might happen.**

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there is a “grey zone between 23 weeks’ and 25 weeks and 6 days’ gestation. While there is an increasing obligation to treat with increasing length of gestation, it is acceptable medical practice not to initiate intensive care during this period if parents so wish, after appropriate counselling.”

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A photograph of a Neonatal Intensive Care Unit (NICU) with a blue and white color scheme, showing medical equipment and a clean, clinical environment.

“There is nothing morally neutral about a NICU. NICU’s are horrible, wonderful places. They are the best and the worst of pediatrics. They save many lives and they cause much pain and suffering”.

Lantos, J. 1999, ‘The difficulty of being anti-NICU’, *Literature and Medicine*, vol. 18, no. 2, Fall, pp. 237-240.