

# Ethics and Decision-making

**P**aediatric **E**nd-of-**L**ife national managed clinical **C**are  
**N**etwork) (2019)

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**Dr Chris Kidson**

Consultant PICU & Clinical Lead PELiCaN

**Shelley Heatlie, et al**

Project Manager, CEN & PELiCaN

[nss.pelican@nhs.net](mailto:nss.pelican@nhs.net)

## Prima facie moral rules

Hippocrates: 'To do away with the sufferings of the sick, to lessen the violence of disease and to ***refuse to treat*** those who are over-mastered by their disease'

Mason and Laurie 2006: 'The preservation of life is secondary to that of preventing suffering.'

## Ethical Principles underpin 'best medical practice' - traditional

Beneficence - qualify and quantify, and achieve an artificial threshold? (utilitarianism - maximising 'happiness')

Non-Maleficence - but for a greater foreseeable good? (Kant challenges 'means to an end') ... what of altruistic donation?

Autonomy - self-determination - not applicable to the incompetent minor

Justice - resources / finances (time) - to whom? Political

## Ethical Principles underpin 'best medical practice' - contemporary

- Best interests ... (but illogical as only one '*Best*', therefore '*Quality of life*' assertions)
- Parental authority
- Permitted actions
  - Positive act of 'Commission' and 'Omission'

## Best interests (case law)

Dame Butler Sloss (Re A 2000): ‘best interests [test] encompasses medical, emotional and all other welfare issues’.

Thorpe LJ (Re S 2001): ‘it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination’ and that ‘the infinite variety of the human condition ... defeats any attempt to be more precise in a definition of best interests ... but [allows] attempts at illumination’.

## Best interests (case law)

Ward J (Re A (conjoined twins) 2001): ‘the analytical problem is to determine what may, and what may not, be placed in each scale and what weight is then to be given to each of the factors in the scales’

## But weighting is not equal ... conscious awareness

Holman J (2006): 'No court has yet been asked to approve that against the will of the child's parents, life support may be withdrawn or discontinued, with the predictable inevitable and immediate death of ***a conscious child with sensory awareness and assumed normal cognition***' ... 'with the single more important source of pleasure and emotion to a small child, his relationship with his parents and family'.

## Neurological significance ...

Cognitive disability more weight than physical disability

- Mental impairment may ... threaten the sense of ... self identity. It is likely that incompetent minors will be disadvantaged by unsubstantiated assumptions made by able bodied adults.
  - Donaldson J (Re C): 'intellectual function [is the] hallmark of our humanity'
  - Harris (2005): personhood philosophy (the potential for a person to value its own [continued] existence).



# Physical disabilities

The negative reflection:

- We talk of difficulties / disabilities, not capabilities (wrapped in a 'quality of life' assertion)

Baseline function (risks negative discrimination by able bodied adults) +/- acquired morbidity

## Mental and physical injury

Mason and Laurie: Do we want a society in which the right to life depends upon achieving a norm which is largely measured in material terms?

Glover (1990): life and consciousness are needed to experience a 'life worth living'

## How much burden is acceptable? (saving the liveable life)

An organ-specific burden (neuro-cognition)

- McLean: ‘fallacy of believing that we can take our own life experiences [project our personal response to an altered (uncertain) future] and translate them into someone else’s reality’
- Lord Donaldson: ‘the decision can only be made in the context of the disabled person viewing the worthwhileness or otherwise of his life in its own context as a disabled person’

A cumulative multi-system burden

An ability to ‘overcome’ the burden

## Internal reflection?

Has anyone considered that a life may be so burdensome or that the ability to enjoy life's positive experiences are so remote that a patient may actually be benefited from their death? - Templeman (1991) suggested there might be.

- Paradox – severe cognitive disability or depressed level of consciousness – the patient may not be aware of their disadvantage
- CK: Is there an ethical difference between a function that has previously been mastered and is lost to one that has never been acquired? Do we perceive a loss to be a greater affliction and viewed with greater scepticism - even though the end result is the same?

## Making difficult decisions

CK: How much objective evidence is needed to inform a subjective value-laden judgements?

- How much hierarchical authority is awarded to the tenet, and the person stating their opinion?
- Who can decide on which tenet - level of expertise?

CK: 'inherent to our decisions is the fact that we accept the risks on behalf of our patients but do not have to live with the burden of their consequences'.

## Proxy-decision-makers ...

CK: Balance a 'guess' at what the child would have chosen for themselves with what is an acceptable treatment burden to impose upon the child.

Extremes of outcomes:

- Get it right: save a life that can be experienced
- Get it wrong: burden / harmful / existing, not living; how much cumulative dependency upon invasive procedures and dependency upon medical technology?

## Why are we frightened...to say 'no'?

Bias to intervene - death is not an acceptable outcome but an absolute loss and a failure to do good

Philosophical: Failure to respect 'the sanctity of life'

- Do we not offer more respect to the sanctity of life if we award value in being able to live the life?

## But who has authority to decide?

Munby 2004: 'Doctors can properly claim expertise on medical matters but they can claim no special expertise on the many non-medical matters which go to form the basis of any decision as to what is in a patient's best interests'

Holman MB, 2008 ...ethical decisions... 'must be made by the doctors [as] judges are neither qualified, nor required, nor entitled to make' of the best interests test, to include, 'every kind of consideration capable of impacting on the decision ... medical, emotional, sensory (pleasure, pain and suffering) and **instinctive**'.



## Do the parents have the authority?

How able are parent's to make such profound, life long decisions?

Lord Templeman (Re B 1981): While '*great weight ought to be given to [parental] views*', the shock of learning of the diagnosis would have had an impact on their decision-making abilities.

Waite J (1997): 'The greater the scope for genuine debate ... the stronger will be the inclination of the court to be influenced by ... the best interests of the child ... will be taken by the parent to whom its care has been entrusted by nature'.

But ...

Dame Butler Sloss (Re MB 2008): 'The graver the consequences of a decision, the commensurately greater the level of competence is required to make the decision' ...Competence may be affected by confusion, shock, pain, fear, drugs...(+ fatigue?!)

Is it correct to award the parents greater authority the greater the impact of the decision, especially when their decision-making capabilities may be detrimentally affected?

## The value of parental views

Prof Myra B-L 2007: 'Parents choose options with infinitesimal odds because the prize they sought was of immeasurable worth'

...

But how do they know that they are going to be able to cope (innocent siblings)

## The value of the ACP and CYPADM forms

Pensive reflection out-with acute emotional trauma with a trusted healthcare professional

For the receiving doctor in a crisis:

- \* A life-limiting diagnosis is acknowledged
- \* A discussion has occurred
- \* A plan has been formulated
- \* A responsible healthcare professional can be identified

## My Approach

- Seek objective evidence to demonstrate positive interactions, rather than negative experiences (video-clips?)
- Justify the intended treatment - reduce symptoms and prolong life - 'does the end justify the means' (although Kant would disapprove)
- Consider the ultimate gains - conscious awareness: what does the patient gain from being alive; what positive virtues does the family gain from the patient being alive?

## CEC Summary: Risks (harms) 'v' benefits (value) + healthcare economic evaluation

Cumulative consideration of:

- anticipated disease progression
- the burden of treatment to achieve the intended outcome
- the likelihood of treatment success
- the foreseen consequences to jeopardise the goal
- the opinions of the child's advocates (parents and AHPs) - what would the child choose for themselves?)

## The Legacy

Hedley J (Wyatt 2004): 'I prefer to determine ... what is the best that can be done' ... 'baby's best interests required a 'good death ... not under anaesthetic, not in the course of painful and futile treatment, but peacefully in the arms of those who love her the most'.

Prof Craft 2011: 'Death with dignity in an inevitable situation can be thwarted by aggressive attempts to save life'

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Can there ever be a situation more devastating for a parent than having to face the end of their child's natural life?

- \* Saunders 2008: 'How people die remains in the memory of those who live on' ... experiences shape the child's legacy, the family's grief...



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## PCCM 2019: 'A Call for new Guidelines and Research in PICU End-of-Life and Bereavement Care'

- When a child dies, parents live their worst nightmare ... which is re-lived ...
  - \* Associated with mental health - PTSD, anxiety, depression
  - \* Associated with organic pathology - cancer, MI, CVAs, MS
  - \* Associated with significant life events - financial, social

# PELiCaN - demand

- Chisp 2 (2018): Palliative care: 2200 babies, children, adolescents / year become unstable or deteriorate, of which 200 will die
- An additional 200 acute deaths (patients not known to Palliative Care)

# PELiCaN - the task

## My question ...

- \* Would we not all want to be involved with painting the last scene of our own lives'? (In charge of our own destiny)
- \* ... then we should help our patients and their family's paint their own'?
  - \* family-integrated
  - \* what matters to me
  - \* realistic: offering deliverable choices

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## Mission

- \* Standardise the process and delivery of paediatric end-of-life care for all ages, all diagnoses, all illness trajectories, pan-Scotland
- \* Increase deliverable family choices (hospital, hospice, home)
- \* Improve patient and family experience (and outcome) of care

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I share a sentiment:

A recently bereaved father said to me ... *'it is just not possible to make a movie that captures the emotions we feel and the admiration we have for you and your team. Not even the greatest movie. It is just not possible'*.

If only his sentiments could be felt by all our families perhaps the horrific burden that is bestowed upon them may be a little less traumatic...

[nss.pelican@nhs.net](mailto:nss.pelican@nhs.net)

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Thank you

[nss.pelican@nhs.net](mailto:nss.pelican@nhs.net)

# PELiCaN - how to?

- Road shows (exploring wishes and opinions: local possibilities and appetite)
- Work streams (data, educational / training, quality assurance, adjunct (psychology, national ethics committee, organ and tissue donation))

## Key Principle

- \* Collaborative universal working - we all help each other to achieve 'these goals'
- \* Central 'hub' being the 'web-site' - shared populated information and contacts
- \* Display real-time 'pins on the map' - Red, Amber, Green - ?mobile workforce??

# PELiCaN - stakeholders

- Medical
  - \* Palliative Care
  - \* CEN
  - \* Cancer MSN
  - \* Neonatal MCN
  - \* Acute Services
- Social
  - \* Financial / employment / accommodation / family members
- Third party
  - \* Agencies and Support / charities / voluntary sector



# PELiCaN - problems

- The subject is of *high profile* (the recent cases adorned within the mass media); it is '*current*' and arouses deeply entrenched *cultural, religious, spiritual* beliefs. It can challenge our essence of *humanity, our purpose, philosophy*.
- Insidious illness trajectory and care needs (personnel, medication, equipment)
- Ethics - the holistic burden of patients living in lower states of health, more dependent upon medicine (as a discipline)
  - \* decisions: made by the right people, based on understanding the right information, at the right time for the right reasons
- Infrequent: changing demand, inequitable service delivery = inequitable choices + inequitable experiences + governance of maintaining skills

## The future?

- Bodies of 'repute' to raise the profile and collate opinions - ?  
Consultations papers / Networks to inform government
- Lord Browne-Wilkinson (Bland 1993) - warned that existing law may not provide an acceptable answer to the new legal questions which modern medicine has created. He raised concern that some dilemmas lie outside of the area of legitimate development of the law by judges and suggests that *'society, through the democratic expression of its views in Parliament, [should] reach its decisions on the underlying moral and practical problems and then reflect those decisions in legislation'*.