



Where angels fear to tread or In the Zone



On what should decisions in the care of critically ill neonates be based? The Zone of Parental Discretion and its role in medical decision making in neo-natal care

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Introduction



- Nature of the session - interactive (as far as possible) exploratory
- A case
- What makes this case so ethically challenging?
- The Zone of Parental Discussion tool
 - How it may meet the ethical challenges
- Applying the ZPD to the case
- Problems in applying the ZPD: harm
- Wider problems with the ZPD
- Conclusions

Introduction



- My original aim
 - To ask where, when, and why we might move between a substantive and a process approach (e.g. from making judgements about, say, best interests, to agreeing to abide by a decision of, say, the parents or an ethics committee)
- The ZPD ‘tool’
 - Is part of a process (a decision tool for a clinical ethics committee faced with disagreement between clinicians and parents) but sets out substantive criteria for deciding whose preference (that of the clinicians or that of the parents) should be acted upon
- So focus has narrowed somewhat
 - To a particular circumstance (parent-clinician disagreement)
 - To a particular approach

A case*



- Baby P is a 10-day-old male infant, born at 26 weeks, and now in NICU. It is unclear at this stage what developmental and medical problems are likely to arise from his prematurity. Following complications, baby P is diagnosed with Hypoplastic Left Heart Syndrome (HLHS). The normal procedure for HLHS is a series of operations over several years. The MDT's view is that treatment is likely to be beneficial to Baby P in the long run, though burdensome in the short term. They advise the parents that he should have the first of the operations. But Baby P's parents are refusing the surgery. They are members of a sect† that believes that the natural and the good are one and the same, and view HLHS as natural. Their beliefs are based on the teachings of a little known mystic and poet of the C19th. Without the operation, Baby P will likely die in a month; but with it, there is a reasonable chance that he will live into adulthood.

- *Case adapted from McDougall, Delany & Gillam (eds) *When Doctors and Parents Disagree* (2016) p.1. The original case is based on actual cases, anonymised.
- †This is a mythical sect.

Challenges of the case



- Desire to act in the child's best interests
 - What are these?
 - Whose view of them is to count?
 - How certain can we be of the outcomes of intervention?
 - What will happen if the parents' preference is overridden?
- Significance of parental autonomy
 - Generally, it is the parents' right to make decisions for their children
 - As a result, it is parental values which drive decisions about children's lives
 - But such rights have limits - where do they lie?
- Concerns about the parents' rationality
 - E.g. in this case, their adherence to mystical ideas

The Zone of Parental Discretion tool*



- [NB: this is my account - my apologies for misunderstandings etc.]
 - Introduced in the context of a clinical ethics committee seeking to decide cases in which health professional and parent choices clashed and the clash could not be resolved
 - Two sets of questions are asked:
 - Questions about harm from the parents' decision
 - Would the decision lead to probable harm to the child?
 - Questions about harm from overriding the parents' decision
 - Would overriding the parents' decision lead to greater probable harm to the child?
- *See Gillam (2010) Children's Bioethics and the Zone of Parental Discretion *Monash Bioethics Review* 29:9, 1; Gillam (2016) The Zone of Parental Discretion: An ethical tool for dealing with disagreement between parents and doctors about medical treatment for a child *Clinical Ethics* 11, 1; McDougall, Gillam & Gold (2016) The Zone of Parental Discretion. In *When Doctors and Parents Disagree*

How the ZPD approach meets challenges



- Desire to act in the child's best interests
 - Best interest concerns are set aside
 - The threshold for a decision to be in the ZPD is 'probable [significant] harm'
 - Recognition of the possible costs (to the child) of overriding the parents' decisions
- Significance of parental autonomy
 - A clear limit to parental autonomy is set: within the ZPD the parents' decisions stand; outside it, they do not
- Concerns about the parents' rationality
 - This is not a focus - it is the outcome of the decision that matters

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Applying the ZPD to the case



- Question about harm from the parents' decision
 - Would the refusal of intervention lead to probable [significant] harm to the child (compared to doing the intervention)?

Applying the ZPD to the case



- Question about harm from overriding the parents' decision
 - Would overriding the parents' decision lead to probable harm to the child (compared to doing the intervention)?

Problems in applying the ZPD: harm



- It is difficult to describe/define harm
 - Note: usually defined in terms of *a set back to a person's interests*
 - What is an *interest*?
 - Does a person have a single interest *or* a collection of interests?
 - What is the single interest *or* what interests make up the collective?
 - What are a very young baby's interests?
- It is difficult to assess harm
 - If it is a collective, what weight does each aspect receive?
 - When is a harm great enough to be a 'significant set back' to a person's interests?
 - What level of probability is required?

Wider concerns about the ZPD tool



- Over restriction of parental decision making rights
 - It is for the parents to judge what is harmful
 - Essentially the borders of the ZPD are set by the health professionals (or by clinical ethics committees) - paternalistic
- Under restriction of parental decision making rights
 - The focus on absence of probable (significant) harm means
 - Improbable large benefits foregone (e.g. from vaccination)
 - Improbable (significant) harm risked (e.g. from not having vaccination)
- Over restriction of (legitimate) health professional autonomy
 - Appears to support non- or non-significantly harmful but futile interventions
 - E.g. tests seen as un-indicated, aesthetic surgery

Conclusion



- Any tool should be used only where it is appropriate
- The range of contexts in which the ZPD might be appropriate is still being discussed